

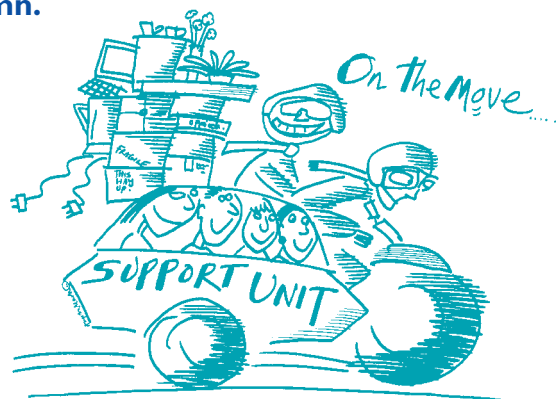
# CONSUMERS IN NHS RESEARCH SUPPORT UNIT

# NEWS

Winter 2002

Welcome to the first newsletter of 2002. The year has already brought a great deal of change. We have a new office after moving to Eastleigh at the end of January. And, sadly, we say goodbye to Bec Hanley, who has decided it is time to move on having established and directed the Support Unit and supported *Consumers in NHS Research* for the last five years. We wish her well in her new role.

In this newsletter we hear about some research projects involving people from traditionally marginalised groups, and there are updates on work being done in our expanded role to include Social Care and Public Health research. There is news of an exciting new study on consumer involvement in research, and more details about the *Consumers in NHS Research* national conference this coming Autumn.



## The Support Unit has now moved !

At the end of January the Support Unit left the Help for Health Trust and moved to new offices in Eastleigh, near Southampton. We are now under the umbrella of the National Cancer Research Network and employed by the University of Leeds. We will be carrying on our work much as before, and building on the work already done, as well as expanding into new areas.

Please note our new contact details on the back page, including changed e-mail and website addresses. Unfortunately, due to some hitches in getting our new IT and telephone system up and running, you may have had some difficulty reaching us recently. We do apologise for any inconvenience.

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## Announcing a seminar on consumer involvement in public health research

The seminar - which will explore how to involve consumers effectively in public health research - will take place in London on Tuesday 21st May 2002 from 10.30am to 4.00pm.

The seminar is for people who are involved in public health research, such as those who commission, carry out, and use research. This includes members of the public, voluntary sector organisations and practitioners.

During the seminar, public health will be considered in a broad sense. There will be discussion on examples of consumer involvement in diverse aspects of research aimed at improving public health and reducing health inequalities, such as in accessing housing, food safety and drug misuse services. Each session will be focused on how to make consumer involvement work.

There is no charge for this seminar, and consumers who are not public health related professionals may be eligible for expenses and an attendance fee. Please note there are a limited number of places available. For more details and an application form, contact Barbara Dawkins at the Support Unit.

# Support Unit News

## *And it's good bye from her...*

As some of you will know, I left my job at the *Consumers in NHS Research Support Unit* at the end of January. After a few weeks well earned (well, maybe not that well earned) holiday, I'm joining the Multiple Sclerosis Society in March as head of research & information. So I'll be retaining a big interest in the involvement of consumers in R&D.

I've really enjoyed my work for *Consumers in NHS Research* and I'll be sorry to move on, but after nearly five years I feel I need a new challenge.

I've been reflecting on the last five years, and want to remind everyone reading this how far things have come. I don't think this is down to any one individual or group – more a general groundswell of opinion and activism, as well as some changes in policy brought about by lobbying from consumers and many supportive researchers who understand the value of consumer involvement in R&D.

Five years ago, it seems that most researchers and funders working in NHS R&D (and in other areas of health services

research) had little or no concept of how consumers could (and should) be involved in R&D, nor how this involvement could improve the quality of research. Five years on, the Research Governance Framework, as well as many other national, regional and local policies, includes a requirement to involve consumers in R&D. Many more consumers are involved in R&D, and often to a greater extent.

The next step? It would be great to see more consumers as genuine partners in R&D, and to see consumers funded to do research *they* see as a priority. And to see more research which crosses the traditional boundaries of health and social care.

Good luck to my successor, and thanks to the team at the Support Unit for being so fab...

See you at the next *Consumers in NHS Research* national conference on the 7th of November!

- Bec Hanley

## Social Care Workshop

On the 31st of October last year, Shaping Our Lives (a service user controlled national organisation which seeks to develop and advance user defined standards and user involvement in health and social care) held a workshop on behalf of *Consumers in NHS Research*. The workshop was an initiative by the Strategic Alliances sub-group of *Consumers in NHS Research*. The aim was to build alliances with users of social care who have an interest in research, and to listen to the priorities of users of social care with regard to research.

Sixteen service users took part and included people with physical and sensory impairments, mental health service users/survivors and people with learning difficulties. There was a great deal of discussion at the workshop and a variety of views were expressed. There was a strong sense that people wanted to be involved to make change and to raise the profile and priorities of service users in research and evaluation, but people were also wary of getting involved unless they could feel there was really such a possibility. A number of issues were identified at the meeting to follow up. This is now work in progress, and *Consumers in NHS*

*Research* are now discussing and planning specific actions which will go towards making a difference. Participants from the October workshop will be updated as to progress, and a further follow up workshop will be arranged later this year.



## 'MAKING A DIFFERENCE'

### Consumers in NHS Research Third National Conference

*We are looking for contributions to one day of plenaries, discussions, workshops, posters and soapbox sessions to promote consumer involvement in health, public health and social care research at our third National Conference at Harrogate International Conference Centre on the 7th of November 2002.*

In 1998 and 2000, *Consumers in NHS Research* held popular and successful national conferences looking at the involvement of consumers in research and development (R&D). *'Making a difference'* will build on these two conferences. This time, though, we'll be looking at the involvement of consumers in social care and public health R&D, as well as in NHS R&D. This conference is supported by the Department of Health.

We want to look at *how* consumers are involved in research, from identifying topics for research, through to undertaking the research and making change as a result. We also want to look at the *impact* that consumers have on research, and how our involvement has led to change.

The conference will be open to consumers (users of services, patients, carers, lay people, voluntary organisations, self help groups and others) as well as researchers and research commissioners in health, social care and public health who have an interest in consumer involvement in R&D.

This will be a participative conference, with workshops, discussions, a soapbox session and posters, as well as a few keynote speakers. There will also be quiet spaces and places to sit and talk, so that people can choose how many sessions they take part in.

We are looking for contributions in the form of workshop presentations, poster presentation soapbox presentations and discussion topics. If you think you might be interested in making a contribution or would like further information, please contact Rosemary McMahon at Professional Briefings on 020 7233 8322.

For those who would like to participate in this conference we will be sending out registration forms in May. If you are not already on our general mailing list then do contact the Support Unit with your details so that we can ensure you receive a registration form.

## News about the Website

An Induction Pack has now been developed for new members of *Consumers in NHS Research*. Although this is an internal document we will shortly be placing it on our website as it will provide a useful guide for those interested in how *Consumers in NHS Research* actually functions.

Now that the website has moved, it means that we have overcome one of the technical hurdles which had delayed getting the public Consumer Involvement Database on the web. However there are still one or two hurdles to go, and we will keep you updated.

We are planning to redesign, improve and expand the website altogether later in the year, and we would welcome any ideas and suggestions you may have.

## Who are the Support Unit Staff?

The core staff are:

- Sarah Buckland, Acting Director  
E-mail: sbuckland@conres.co.uk
- Barbara Dawkins, Administrator  
E-mail: bdawkins@conres.co.uk
- Roger Steel, Development Worker  
E-mail: rsteel@conres.co.uk
- Helen Hayes, Information Officer  
(currently temporary contract)  
E-mail: hhayes@conres.co.uk

For the present all the above can be contacted on Telephone: 023 8065 1088.

On temporary contract until the end of March:

- Brigid Morris,  
Social Care Research Liaison Officer  
(2 days pw)
- Jane Royle  
Public Health Research Liaison Officer  
(1.5 days pw)

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## ‘HEALTHY FUTURES’

### A consultation with children and young people on their views of health services in Camden and Islington

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*“I don’t think that there is anything really that could have been much better... I think it was one of the best hospitals to which I have been, actually.”*

*(Female, 13)*

Earlier this year, Camden and Islington Health Authority commissioned Barnardo’s and City University to carry out a consultation in Camden and Islington to ask children and young people what they think about the health services they receive in the area. The project – *Healthy Futures* – runs from June 2001 to March 2002 and includes direct work with around 140 children and young people aged 4-18 living in or using health services in Camden and Islington, as well as contact with a much greater number of children (we hope!) through the *Healthy Futures* website ([www.healthyfutures.org.uk](http://www.healthyfutures.org.uk)). The brief is to consult generally about what works for children and young people in the way that services are provided.

*“They didn’t tell me that if I don’t want these sorts of pills you can have another pill, they didn’t tell me that, they just said that this pill is the best one you can have... But I didn’t want that pill because there was something in it that my mum said wouldn’t be good.”*

*(Female, 13)*

The consultation draws on children and young people’s understanding of health services and who provides what kind(s) of care; their positive experiences of health care; and also issues which have been less positive and the learning from these. From the outset, the consultation has aimed to be an enjoyable experience for the children who take part and to ensure that children and young people feed into all stages of the project. The end products of the project will be a report for adult stakeholders and one for children and young people, a web site, and a learning event for NHS staff on consulting with children and young people.

*“They brought [the equipment] to my house so I could practise at home... personally I would have preferred to go to them, because in those days I was just at home all day and I wanted to get out and about.”*

*(Male, 19)*

Access to children has mainly been gained through local NHS hospital trusts and mainstream schools and youth projects. A range of child centred methods have been used in group settings and one-to-one interviews. With nursery children we used role-play with teddy bears, toy doctor’s kits, storybooks and other visual prompts. In primary schools we additionally used draw-and-write, sentence completion and word association techniques. When consulting with older children, discussion was stimulated using more sophisticated group word and discussion games. Work with disabled children was carried out in special schools in close collaboration with teachers, using lessons in which they were already exploring embarrassing/scary/happy situations.

We hope that by using attractive and fun activities, the children feel that they also gain something from participating.

*“You can play with toys while you’re waiting better than the other one [doctor] you just do nothing.”*

*(Male, 6)*

Data collection is coming to a close and emerging themes from the preliminary analysis are confidentiality and trust (teenagers), support to cope with going to the doctors/being ill and the importance of parental care (nursery age). Many of the children and young people we have spoken with, from the little ones in nurseries to those who have left school, have been concerned with waiting times and waiting room facilities, and communication issues between staff and patients.

*“My mum’s beside me, they’re saying like ‘are you sexually active?’ You’re just like: ‘My mum! Me and my mum - I don’t wanna answer.”*

*(Female, 13)*

One expected outcome of the consultation is the development of lasting systems for continuous dialogue between young people, the Health Authority and local trusts, and the project is exploring existing local systems of consultation to learn from these. We are also

currently carrying out a range of literature searches to ensure that we include relevant published material and are keen to hear of similar work carried out in other parts of the country. So do let us know if you are aware of any 'grey' literature or similar projects carried out by students as part of their dissertations, undertaken for audit purposes or in the hospital schools, architects/estates departments or

other Health Authorities or Health Action Zones. *Healthy Futures* can be contacted via Kristin Liabo on e-mail [k.liabo@city.ac.uk](mailto:k.liabo@city.ac.uk) or direct phone line 020 7040 5970, or you can write to: Kristin Liabo, Institute of Health Sciences, City University, Bartholomew Close, London EC1A 7QN.

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## Successful consumer involvement in health research: what does it mean and how do we measure it? An invitation to take part in a Delphi Study.

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What does it mean to involve consumers successfully in health research? How do you measure successful consumer involvement? A team from the School of Health and Related Research (SchARR) at the University of Sheffield - Rosemary Telford, Jonathon Boote, and Cindy Cooper - will be carrying out a research project over the next few months to try to answer these complex questions.

In an important stage of this research we intend to use the Delphi process; a research technique used to develop agreement among a group of people using a series of postal questionnaires. This Delphi process will provide an opportunity for a group of consumers and health researchers to develop *principles* of successful consumer involvement in research, as well as measurable *indicators* of each principle. The project aims to recruit a group of about 100 researchers and consumers for our Delphi process.

If you have knowledge and/or experience of consumer involvement in research; have an interest in ideas about consumer involvement in research; and you are willing to share your views with others, please get in touch with Jonathon Boote for an informal discussion and to find out more.

The principles and indicators of successful consumer involvement in research developed during the Delphi process will be incorporated into a checklist. This will be used in a national survey of health research projects to establish a baseline assessment of the degree to which consumers are currently

being involved successfully in research. If you do receive a checklist from the project in the coming months, asking you to reflect on the degree of 'successful consumer involvement' in your research, we do hope you will take the trouble to fill it in and return it.

If you would like more information please contact the research team:

- Rosemary Telford 0114 222 0754  
[r.telford@sheffield.ac.uk](mailto:r.telford@sheffield.ac.uk)
- Jonathon Boote 0114 222 0754  
[j.d.boote@sheffield.ac.uk](mailto:j.d.boote@sheffield.ac.uk)
- Dr Cindy Cooper 0114 222 0743  
[c.l.cooper@sheffield.ac.uk](mailto:c.l.cooper@sheffield.ac.uk)



# Examples of consumer involvement

## 'It's Your Choice!'

*By Mark Brookes, Project Worker at Values Into Action*

In 1999 I saw an advert for a Research Assistant on a project at Values Into Action (VIA). The project was called 'Making Decisions' and it was all about people with learning difficulties getting choice and control in their lives.

At the time I was working at *People First Havering*, a self-advocacy group in Essex. I was helping set up a training company but the project funding ran out so I needed another job.

I applied for the job at VIA and was called for the interview. I got the job and started in November 1999. I was employed at VIA on the same pay scale as everyone else and on an equal contract. I was an equal member of the staff team and I got involved in lots of VIA's work.

I worked on the project with my colleague Stephanie Beamer. Our job was to find out how people with learning difficulties and high support needs can be supported to make choices. People with 'high support needs' can have physical disabilities, health needs, and 'challenging' behaviours as well as learning difficulties.

We spent the first few months finding out all about making decisions and making contact with lots of people. Stephanie recruited ten people with high support needs and their supporters from across the country to get involved in the case study work. My work involved going out to meet people with learning difficulties in self-advocacy groups, day centres and colleges across the UK. I designed a workshop called 'It's Your Choice!' and I produced a flyer to recruit groups. We had a fantastic response! Over five months, I travelled to sixteen groups from Glasgow to Bournemouth and ran the workshop for over two hundred people.

It was my first time in doing research. The hard part for me was putting the report together, deciding what bits of the report went where. The success I think was the workshops because a lot of people came along. It was good to find out that people with learning difficulties were making some choices. This project was a good experience and I enjoyed doing it.

I made notes after every workshop. I found out that people with learning difficulties get the chance to make some

choices but a lot of people didn't have much of a chance to really make choices.

Stephanie and I gathered a lot of research data. We spent a long time working out what it all meant. Then we spent a lot of time writing our books. Stephanie wrote a big report 'Making Decisions: best practice and new ideas for supporting people with high support needs to make decisions'.

I took a lead on our accessible workbook and audiotape called 'It's Your Choice!' We got an illustrator to do pictures for us and we worked with the designer to lay out the book in a fun way. We also spent time in a studio making the tape.

Finally, Stephanie and I planned and ran three events to launch our work. We ran seminars for people with learning difficulties in Edinburgh and Manchester, which were great fun. Then we ran a big conference called 'Everyone Can Decide' in London. I chaired the conference. The project ended in November 2001.

I felt it was good being part of a team, even though there was just two of us. I don't think I made a difference as a person with a learning difficulty, I just felt part of VIA and one of the team. I think there should be more jobs for people with learning difficulties. And there should be more links with groups so people know what each group is and what it is doing. Finally, people with learning difficulties should be more involved in what projects should be about.

If you want to find out more about our work or order our books, give us a ring on 020 7729 5436. Or contact us at Values Into Action, Oxford House, Derbyshire Street, London E2 6HG E-mail: [general@viauk.org](mailto:general@viauk.org) Website: [www.viauk.org](http://www.viauk.org)

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## Black and minority ethnic user involvement in research

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*The REU is a leading national agency working to develop appropriate social care services to Britain's black and minority ethnic communities. The organisation draws upon a wide range of funding sources. Here, Tracy Bignall describes consumer involvement in their research work.*

The social research sector has experienced a change in focus on the role of respondents in research. We have seen a growth in user involvement and research that is led by or managed by groups of respondents, such as people with learning difficulties or young people. Yet it is questionable whether black communities play an active role in setting the research agenda.

As a national agency carrying out research, consultancy and training in social care and race equality issues, we aim to promote better social care for Britain's Asian, African Caribbean and African communities. Our work covers a wide range of health and social care areas including child protection, social work practice, disability, children and families, mental health, and older people. All the research we undertake attempts to involve users. Below is a description of how one project involved users.

In 1998 we undertook a project looking at the experience of young black disabled people (aged 16 to 25 years) of independence and independent living. It is widely accepted that disabled people should do more than be 'subjects' in a piece of research, therefore this project involved young disabled people in several ways.

As with most funded projects there was an advisory group of professionals offering help throughout the process. In addition, we involved two reference groups of young black disabled people in different areas of the UK. One was a Caribbean group of people with learning difficulties, whilst the other was an Asian group of people with mixed impairments.

Their role was to act as a point of reference at different stages of the research. For example, their views were sought about the type of questions we intended to ask young people. Their comments led us to change some of the questions on the interview schedule. Also, some of our approaches to this work, in particular that we address information to the young black disabled people themselves rather than their parents or carers. We also had help from two black disabled consultants.

Once the fieldwork was done and the draft report completed, the young black and minority ethnic disabled people were provided with the opportunity to assess and review our analysis of the interviews to guard against the tendency of past research to abstract and distort the experiences of black people.

Further dissemination not only produced a summary document for professionals, but also a summary for people with learning difficulties. Here again, two young people who had been interviewed for the research gave their suggestions on the layout, wording and content of the paper. In addition, a young black man with learning difficulties working for a disability organisation offered his advice independently.

At the conference to launch the report, young black disabled people participated in running workshop discussions and making presentations to the main conference.

Ultimately, for user involvement to be effective, the young black disabled people needed to have the right support in order to make a contribution. Language and sign language interpreters, providing information in different formats and time, ensured these young black disabled people were involved in the research design and process, as well as (hopefully) feeling their contribution was valid.

*Tracey Bignall is a Research Assistant with the REU. For more information, contact her at REU, Unit 35 Kings Exchange, Tileyard Road, London N7 9AH. Telephone: 020 761 96229.*

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## NOTICE BOARD

### Listening again...

The National Co-ordinating Centre for Service Delivery and Organisation (SDO) R&D is conducting a second 'National Listening Exercise' (the first was conducted in 1999) to inform the development of the SDO Programme over the coming years. A range of user groups will be invited to take part in this process. A fuller report will be made available via this newsletter when results are available in Summer 2002. Further information can be found at: [www.sdo.lshtm.ac.uk](http://www.sdo.lshtm.ac.uk)

# NOTICE BOARD

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This is a regular column which can be used to advertise events, initiatives and publications about consumer involvement in R&D. If you would like to put an article on our notice board please contact the Support Unit.

## New Consumer Panel for Cancer Research

The Academic Palliative Medicine Unit at the University of Sheffield has recently set up a Consumer Panel funded by the North Trent Cancer Research Network. The funding will be sufficient for providing administrative support, expenses and payment for involvement. The Panel has been recruited from a wide variety of sources, and currently there are 13 members. A two day training has already been provided. The Panel will be evaluated by the Trent Institute for Health Services Research. For more details about the Panel and the training, contact Tony Stephens on 0114 271 1706 or e-mail [t.stevens@sheffield.ac.uk](mailto:t.stevens@sheffield.ac.uk)

## Knowing How

Folk.us in Exeter have recently published '*Knowing How – A Guide to getting involved in Research.*' This short guide is based upon the findings of a project commissioned by the Empowerment sub-group of *Consumers in NHS Research* and published last year in the report '*Small Voices, Big Noises, Lay involvement in health research: lessons from other fields*' written by Lisa Baxter, Lisa Thorne, and Annie Mitchell (2001). '*Knowing How*' - written by Lisa Thorne, Rachel Purtell, and Lisa Baxter is an accessible guide taking the reader through the basic questions and answers about getting involved in research. For further details contact Katherine Gomme at Folk.us on Telephone: 01392 264660 or e-mail [folk.us@ex.ac.uk](mailto:folk.us@ex.ac.uk)

## 10<sup>th</sup> Cochrane Colloquium

The Cochrane Collaboration is an international organisation that aims to help people make well-informed decisions about health by preparing, maintaining, and ensuring the accessibility of systematic reviews of the benefits and risks of healthcare interventions. The Collaboration actively seeks to involve consumers in the preparation of systematic reviews as part of its action plan to improve the quality of reviews.

The Collaboration are holding their 10th Cochrane Colloquium in Stavanger, Norway on the 31st July to the 3rd of August 2002. More details are available from Nicola Thornton, UK Cochrane Centre, Summertown Pavilion, Middle Way, Oxford OX2 7LG. Telephone: 01865 516300 E-mail: [nthornton@cochrane.co.uk](mailto:nthornton@cochrane.co.uk)

## Gene Watch UK – New Report

'*Giving Your Genes to Biobank UK: Questions to Ask*' is a new report written by Kristina Staley for Gene Watch UK and published in December 2001. This report looks at the important issues that anyone being asked to give a sample of blood or cells to a biobank needs to consider, and the questions they might ask. Contact: Gene Watch UK, The Mill House, Manchester Road, Tideswell, Buxton, Derbyshire, SK17 8LN. Tel: 01298 871898 E-mail: [mail@genewatch.org](mailto:mail@genewatch.org)

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## About the Support Unit...

The *Consumers in NHS Research Support Unit* is based in Eastleigh near Southampton. Our role is to:

- Provide information, advice and support to consumers, researchers and those working in the NHS on consumer involvement in health research
- Commission and undertake research about the involvement of consumers in health research
- Produce publications and reports
- Organise seminars, conferences and workshops on consumer involvement in health research.

Please contact us if you'd like to know more, would like to be on our mailing list, are interested in becoming an Associate Member, or wish to contribute to our next newsletter.

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